These are suggestions from Illinois Citizens for Better Care for the Illinois §1115 waiver. Illinois Citizens for Better Care is the Illinois long-term-care residents' advocacy organization.

We assume you will be getting volumes of suggestions, so we have tried to keep these terse. If you want us to elaborate on any of them, please let us know.

1. Many people go into nursing homes because of a short-lived physical or mental health crisis, and remain mostly because they have no other place to live. There are a lot more people entering nursing homes who have a home, than who are homeless. They effectively become homeless (other than the nursing home) because they cannot afford to pay rent/utilities with a spend-down of $30/month. While in the nursing home for, say, post-stroke rehab, they lose their home, their furniture, kitchen equipment, dishes, most of their clothes, and virtually all of their other person property.

IDHFS now allows people entering a nursing home who some likelihood that they will be able to move out, to keep, at most, about $100/month, the AABD standard. To allow people to return to their homes and property, IDHFS should:

a. Identify people likely to be able to return home within six months, initially before nursing home admission, and again at least once within the first month of admission ;

b. Allow these people to keep, in addition to the $30, whatever are their actual monthly property costs. (In other words, increase their personal needs allowance, or keep it at the community standard. For people on SSI, supplement their SSI from the $30 SSi will pay, to allow them to keep their homes.) Keep this up for at least six months; longer, if discharge is imminent within a month or two.

c. For nursing home residents who need some kind of 24 hour supervision, but no longer need 24 hour nursing care, set aside some SLF apartments for short-term housing until they can return home. Allow them to pay their monthly property costs while in the SNF (if necessary, paying to supplement their income so they can do both.)

d. Require a home visit by an occupational therapist for every person admitted because of any physical health crisis, to see what home adaptations will be needed/can be made to make the person's home more accessible. (Medicare generally pays for this for its beneficiaries.) Coordinate home adaptations to this assessment. If the person wants this, tailor therapy goals to what the person needs to manage at home. E.g., if the bathroom is too small to accommodate a wheelchair, how many steps the person will have to be able to take (assisted, or unassisted,) to use the bathroom. How many steps she will have to be able to climb – and how high, with or without a railing – because she lives in an apartment building with stairs that cannot be ramped.

e. For people with a mental illness: do an interview, assessment (including home visit, interview with roommates/family, etc) while the person is hospitalized, or otherwise being treated for a mental health crisis, to determine the person's living situation, what needs to be done to keep the home available, acceptable as a safe environment. Tailor hospital discharges to the person's immediate needs, providing whatever supports the person needs to get through the first day, second day, first week, whatever. This may include escorting the person home and staying home, telephone support (calls to and from the person,) grocery shopping, transportation to follow-up care, etc. Again, even with intensive services, avoiding institutionalization in a SMHRF or SNF may be cheaper than trying to find housing for the person, weeks or months later.

2. Improve the quality of care for nursing home resident, to minimize expensive hospitalizations and generally make their lives better

a. Mandate consistent assignement of staff.

b. Require/encourage (don't care which: just get it done) hospitals with a significant number of patients admitted from/discharged to nursing homes with poor quality records, to get their doctors to continue caring for their patients after discharge/accept responsibility for new patients living in the nursing home. Train the doctors about a nursing homes' responsibilities to its residents, including – but definitely not only – following doctors' orders.

c. We understand IDPH is working on some kind of initiative to reduce psychotropic meds being given to nursing home residents without a psych diagnosis (i.e., generally with dementia.) Illinois is currently 49th (worst is 51) on the list of states with inappropriate administration of psychotropic meds. Facilities with high rates of inappropriate psychotropic administration should be identified, staff required to get prescribed training on appropriate dementia care. Family members should be invited to participate in this training. (See d, below.) The IDHFS review process for psychotropics, mandated by the 2010 Illinois nursing home reform law, should be strengthened, and a parallel process implemented for Medicare beneficiaries. Physicians ordering inappropriate psychotropics should be identified, required to have specific training in order to keep nursing home privileges.

d. Starting with the lowest-quality nursing homes, Illinois should organize, train nursing home family councils on care-related issues. Family members should be taught about what is good dementia care (not in generalities, but specifically what it looks like.) They should also be taught to identify specific issues that are likely to indicate/result in bad care. Nursing homes should be required not just to respond to family council requests (which they can do by saying"no,") but to respond appropriately. There should be IDHFS oversight of this process: that is, logging of complaints, someone at IDHFS family councils can go to if the facility is stonewalling or otherwise refusing to cooperate.

e. The lowest-quality nursing homes should be required to partner with good nursing homes to teach staff, do oversight, improve care.

3. Put resources where people are.

For older and disabled people, this means physician, nursing and home care agencies in senior buildings. For children, this means schools. For the latter, this should mean all children in high-poverty-area schools getting services, regardless of whether they have individual Medicaid eligibility. MCO's should be required to coordinate provision of services/billing.

4. There should be quality measures for all providers, and those quality measures should be easily accessible to the public. Individual and aggregate/comparative data should be available both on a website, and at each provider's office.

5. Violence-prevention initiatives should be a Medicaid service. Community mental health agencies should do assessments at juvenile court.